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The Assessment of Senior-Level Nursing Students’ Knowledge Regarding Informal Caregiver Role Strain and the Presence of Role Strain in Informal Caregivers of Dementia Patients

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The Assessment of Senior-Level Nursing Students' Knowledge Regarding Informal Caregiver Role Strain and the Presence of Role Strain in Informal Caregivers of Dementia Patients

by

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ABSTRACT

The goal of this study was to assess senior-level nursing students' knowledge of informal caregivers of dementia patients, their confidence in their ability to work with informal caregivers, and how well they believe their nursing program prepared them to assist informal caregivers. Seventeen (*n* = 17) Bachelor of Science (BSN) nursing students participated in the study. A twenty-four-question survey was emailed to both junior- and senior-level students in the five-semester BSN program at the University of Southern Mississippi (USM). Responses from students of different levels were collected to determine if an accurate understanding of informal caregivers of dementia patients was more prevalent in senior-level students when compared to junior-level students. The survey included a total of four question sets. The first question set required students to select the semester of the BSN program in which they were enrolled at the time of taking the survey. After selecting their semester within the program, students were asked five questions regarding their attitude towards caregivers, five multiple-choice questions assessing the accuracy of their knowledge of caregivers, eight questions focusing on their beliefs on nurses' role when working with caregivers, and five questions determining how well they felt their BSN program had prepared them to support caregivers. The majority of study participants believed they were well-prepared to collaborate with informal caregivers in clinical practice. However, the students' responses to the multiple-choice questions assessing the accuracy of their knowledge indicate that further education on informal caregivers of dementia patients may be required.

Keywords: Informal caregivers, caregiving, dementia, nursing students, role strain

DEDICATION

This thesis project is dedicated to my family, especially my amazing grandparents: Bob and Pat Erichsen, and Wilma and Lou Rizzardi, my wonderful parents: Jess and Wendy Diard, and my fantastic siblings: Logan, Parker, Marc, and Samantha. I could not have gotten this far in my journey without your support and never-faltering love, and I will be forever grateful for all that you have done for me.

I would like to also dedicate this thesis to my closest friend and study partner, whom I would not have met without nursing school: Tatiyana Fleming. I am so thankful for your friendship, the advice you have given me, and the laughter we have shared even during the hardest days.

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LIST OF ABBREVIATIONS

AARP	American Association of Retired Persons
BSN	Bachelor of Science in Nursing
CBT	Cognitive Behavioral Therapy
IRB	Institutional Review Board
USM	The University of Southern Mississippi

CHAPTER I: INTRODUCTION

Background

The term *dementia* refers to a variety of diseases affecting an individual's cognitive function, including skills such as memory and language. A diagnosis of dementia is accompanied by the fear of possessing a chronic condition that may progress so severely that those afflicted will be unable to recall how to accomplish even the simplest of tasks, including toileting, feeding, and grooming. The disease itself is not considered to be rare. Alzheimer's disease, the most common form of dementia, affected approximately 5.8 million Americans in 2019 alone, a number that is anticipated to increase as the population of the United States continues to age (Alzheimer's Association, 2019; Alzheimer's Association, 2021).

Due to the prevalence of the disease, patients with dementia are often seen in healthcare institutions like hospitals and nursing homes. There is currently no cure for dementia. Treatment within healthcare organizations has become increasingly complex, involving a combination of pharmacologic and non-pharmacologic interventions to slow the rate of patients' cognitive decline, as well as supportive care to promote healthy coping skills and acceptance of the disease (Alzheimer's Association, 2019). Most available therapies are meant to aid patients as their cognitive function and physical ability gradually deteriorate. Since dementia can be present anywhere between eight to twenty years from the time of diagnosis to death (Alzheimer's Association, 2019) and causes both mental and physical disabilities, individuals with this disease often require full-time caregiving as the condition progresses (Chiao et al., 2015). The cost of housing inside a nursing home can range from anywhere between $90,155 to $102,200 per year, depending on the specific facility and privacy of the room; similarly, assisted living is roughly $48,600 per year (Alzheimer's Association, 2021). Even if care is provided inside an individual's own home, the average cost of hiring at-home care is $1,012 per week or $52,624 per year, a number that can vary greatly depending on the hours and extent of care required (Alzheimer's Association, 2021). As a result of the high cost associated with nursing homes, assisted living, and hiring at-home care, over half of dementia patients in the United States receive their care from family members or friends, who receive neither monetary compensation for their time nor prior caregiver training and are thus known as *informal caregivers*.

Importance and impact of caregiving

By providing full-time care to individuals with dementia, informal caregivers complete a variety of tasks, including but not limited to: assisting with hygiene, managing financial and legal matters, completing shopping and household chores, arranging healthcare appointments, and providing the dementia patient with emotional and behavioral support (Alzheimer's Association, 2019). Furthermore, by caring for patients with dementia, informal caregivers ensure that these individuals can live in their community for a longer period (Chiao et al., 2015). Because they are not paid, informal caregivers also ensure that care is given to those who would likely be unable to afford it otherwise (Collins & Swartz, 2011).

In addition to aiding the recipients of care, informal caregiving can also provide rewards to those providing care. When prepared with knowledge of the disease process of dementia and trained in how to best offer care and cope with the stress of caregiving, informal caregivers have reported experiencing positive feelings and benefits, including care recipients' gratitude, the development of resiliency, increased feelings of self-worth, and improved family relationships (Bauer et al., 2013; Alzheimer's Association, 2019).

The worth of informal caregivers cannot be overstated, and it is thus critical that their health and overall state of well-being is monitored regularly. Being a full-time caregiver is not an easy task. It is common for informal caregivers to cease working or greatly reduce their hours and decrease their involvement in social activities, so they can tend to care recipients, leaving caregivers with limited income and devoid of a support network (Thompson et al., 2018). Although there may be benefits, caring for a loved one with dementia can also lead to increased stress stemming from financial concerns, lacking knowledge in providing care, and altered eating and sleeping habits (Irfan et al., 2017). This particular form of stress, when seen in informal caregivers, is termed *caregiver role strain* or *burden,* and, if left unaddressed, can lead to a decline in caregivers' physical, psychological, and spiritual health (Thompson et al., 2018), which may cause issues such as anxiety and depression in the caregiver (Irfan et al., 2017). The overall physical and mental exhaustion associated with being a full-time informal caregiver may also lead to impaired judgment, which results in an increased risk of injury for the care recipient (Mathias, 2019).

Role of nurses

In order to prevent caregiver role strain, healthcare providers should be trained to recognize the signs of the condition and understand what interventions and support they can provide to informal caregivers (Greenwood et al., 2010). Nurses often spend more time with patients than other healthcare professionals. They are in an ideal position to address the presence of caregiving burden before it causes other health issues because of their constant and continuous interactions with patients and patient caregivers (Zegwaard et al., 2015). Nurses are caregivers as well, however they are considered to be *formal caregivers* due to their training and paid compensation in providing care to patients (Hagedoorn et al., 2019). As a result of their experience as professional caregivers, nurses possess information they can distribute to informal caregivers. Nurses can share their knowledge of dementia and teach informal caregivers about medications and techniques to manage care recipients' dementia, such as creating a safe home environment and maintaining a daily routine. By offering this information, nurses can help alleviate the stress in caregivers that is associated with a lack of knowledge about patients' illnesses and care requirements (Hagedoorn, et al., 2019).

Although nurses are in arguably one of the best positions to collaborate with informal caregivers, previous research studies, while limited, indicate that nurses feel as though they have not received enough training regarding this caregiving population and the associated role strain. Training is needed in order to truly assist informal caregivers of dementia patients (Greenwood et al., 2010). It should be noted that the conducted studies involved nurses already inside clinical practice, including areas like primary care facilities (Greenwood et al., 2010), hospitals (Laparidou et al., 2018; Hagedoorn et al., 2019), and mental health clinics (Zegwaard et al., 2015). Preparing nurses to support informal caregivers upon entry into clinical practice should involve education about informal caregivers and caregiver role strain while nurses are still students within a nursing program (Henelaar et al., 2017). No past research was discovered examining the confidence of nursing students' ability to collaborate with informal caregivers and manage the presence of caregiving burden.

Statement of purpose

The purpose of this thesis is to determine whether senior nursing students within the University of Southern Mississippi's (USM) Bachelor of Science (BSN) program feel that they have been adequately prepared to recognize the clinical signs of role strain in informal caregivers of dementia patients and prevent or intervene with this burden using evidence-based strategies.

Significance to the nursing discipline

Informal caregivers represent a significant population within certain areas of clinical nursing practice where dementia patients are seen, such as home health, geriatric, mental health, general practice, hospice, and medical-surgical nursing. In Mississippi alone, approximately 131,000 individuals were acting as informal caregivers during the year of 2020 (Alzheimer's Association, 2021). Informal caregivers provide much of the aid given to older adults and those with debilitating health conditions, all while remaining unpaid and, on many occasions, uneducated on disease processes and how to best provide care (Alzheimer's Association, 2019; Mark, 2015; Laparidou et al., 2018). Informal caregiving is especially crucial for patients with dementia, as they are more likely than older adults without dementia to require assistance with various tasks because of their condition. Such tasks may be health-related and involve activities like medication administration or mobility assistance (Alzheimer's Association, 2019). Other assistance provided may be associated with cognitive decline and include the management of behavioral changes (Collins & Swartz, 2011), the monitoring of finances, the scheduling of appointments, and ensuring patient safety in the home (Alzheimer's Association, 2019; Mathias, 2019). Protecting informal caregivers from developing role strain and the associated health issues should be an essential component of nursing education (Hengelaar et al., 2017), but little research has been done regarding nursing students' confidence in their ability to assess for, prevent, and intervene with caregiver role strain.

As a result of the noted deficit, this thesis project is significant to both the nursing profession and the University of Southern Mississippi: For the field of nursing research, this thesis may provide insight into nursing students' understanding of informal caregivers, which has yet to be thoroughly investigated. Similarly, the results of this study may reveal a gap in BSN curriculums related to instruction concerning role strain among informal caregivers of dementia patients.

CHAPTER II: LITERATURE REVIEW

Prevalence and strain of caregiving

The Alzheimer' Association (2019) found that, in the year 2019, 83% of the older adults receiving assistance were provided this help by informal caregivers. Of this population, 48% of the older adults receiving care were suffering from a form of dementia (Alzheimer's Association, 2019). Informal caregivers provide extensive, often full-time care to individuals with dementia. Assisting with a variety of tasks, such as bathing, feeding, administering prescribed medications, shopping, scheduling appointments, and monitoring finances is not uncommon (Alzheimer's Association, 2019; Alzheimer's Association, 2021). In addition, informal caregivers are typically closely observing the health of their care receiver. Therefore, caregivers may be the first to notice a decline in care recipients' cognitive or physical well-being; should the dementia patient require treatment in a formal setting, the informal caregiver will also serve as a patient advocate to the care receiver (Hengelaar et al., 2017; Alzheimer's Association, 2019; Mark, 2015). Further investigation revealed that informal caregivers of dementia patients contributed a total of approximately 18.5 billion hours of care in 2018, which was determined to be worth roughly $233.9 billion (Alzheimer's Association, 2019).

Due to their position in providing care to dementia patients who may otherwise be unable to afford or ineligible for receiving care in a formal setting, informal caregivers serve as an important component of the healthcare system (Collins & Swartz, 2011). However, the intensive assistance they provide to individuals with dementia is not without consequence. Informal caregivers have been found to experience significant life changes related to providing care for another individual, such as being unable to finish a graduate or post-graduate degree and neglecting their career (Irfan et al., 2017). In the year of 2019, 57% of informal caregivers had to adjust their work hours to accommodate for the time needed to provide care to an individual with dementia (Alzheimer's Association, 2019). These negative impacts on education and employment status can have a significant influence on caregivers' current and future careers, and contribute to emotional distress (Irfan et al., 2017). Caregivers are also likely to suffer from financial strain related to the act of caregiving. Monetary contributions to care recipients' medical needs, when coupled with decreased income caused by decreased work hours or job loss, lead to financial strain and further distress in caregivers (Alzheimer's Association, 2019; Irfan et al., 2017). In addition to struggling with the management of professional employment obligations, informal caregivers may face difficulties fulfilling other social roles and responsibilities, such as those related to marriage and family commitments (Irfan et al., 2017). Finally, caregivers of dementia patients must adapt to changes in their care receiver, as dementia patients are likely to experience behavioral fluctuations that lead to a need for extensive physical assistance and continuous surveillance (Collins & Swartz, 2011).

Inability to meet the demands of various social roles and caring requirements can lead to a form of stress among informal caregivers known as caregiver role strain or burden (Mark, 2015). This mental strain is often coupled with the poor physical health that occurs because of caregiving demands. Informal caregivers are susceptible to suffering from poorer sleep patterns, reduced immune function (Simpson & Carter, 2013), and are at increased risk of developing chronic health conditions such as depression, anxiety, cardiovascular diseases, and an overall decreased quality of life (Alzheimer's Association, 2019; Irfan et al., 2017). Moreover, increased strain in informal caregivers has also been associated with increased risk of injury among their care receivers (Laparidou et al., 2018; Mathias, 2019).

Clinical manifestations of role strain

Before caregiver role strain reaches a point at which it causes severe issues in psychological and physical health, symptoms may be present. Many of these indicators are psychological in nature, and a caregiver developing role burden may experience feelings of anger towards the care recipient, guilt for becoming angry (Alzheimer's Association, n.d.), denial about the care receiver's disease, anxiety when thinking about the future, irritable mood, and insomnia (Thompson et al., 2018). Additional problems include a decreased ability to concentrate and abnormal removal from social activities (Thompson et al., 2018).

From a nursing perspective, the clinical signs of caregiver burden may not be readily obvious, even though nurses typically spend an extended amount of time working with dementia patients and their caregivers. Moreover, nurses caring for patients with dementia may focus solely on the patient, making it easier for the subtle signs of role strain in patients' caregivers to be overlooked (Zegwaard et al., 2015). Nurses should interact with patient caregivers regularly (Zegwaard et al., 2015), and consider the possible existence of role strain if caregivers appear abnormally preoccupied with or—alternatively—disinterested in the care given to their care recipient, exhibit fear regarding the future and health of the care receiver, or relay to the nurse that their own well-being has declined since they began providing care (Gulanick & Myers, 2017).

Role of nursing professionals in mediating strain

Healthcare providers may be the first to recognize health issues such as dementia and caregiver role strain, and are thus considered a critical component in both the care of patients with dementia, as well as care of the patients' caregivers (Chiao et al., 2015). Nurses especially are in a suitable position to recognize the symptoms and respond to the presence of role strain due to the amount of time they spend working with patients and their caregivers (Hagedoorn et al., 2019; Zegwaard et al., 2015). When nurses are adequately prepared to identify and address role strain, they can provide informal caregivers with education regarding different interventions and resources to help prevent or mediate burden (Demirbag et al., 2017; Chiao et al., 2015). If caregiver role strain can be reduced or prevented, informal caregivers are less likely to develop complications like depression or heart disease (Chiao et al., 2015; Alzheimer's Association, 2019), and care receivers are at decreased risk of being injured or placed in nursing homes early (Chiao et al., 2015; Mathias, 2019).

Methods of intervention

Possible interventions to reduce feelings of caregiver burden can be divided into three groups: psychosocial, psychoeducational, and organizational (World Health Organization, 2017; Morelli et al., 2019). Interventions considered to be psychosocial often involve a trained psychologist and are centered around promoting caregivers' mental, emotional, and social health; psychosocial interventions involve resources such as caregiver support groups and cognitive behavioral therapy (Morelli et al., 2019). Professionally held training sessions to inform caregivers about the disease affecting their loved one and improve caregivers' skills in performing care activities constitute psychoeducational methods of intervention (Morelli et al., 2019). In contrast to psychosocial and psychoeducational approaches, organizational interventions are meant to allow caregivers a brief break from or additional assistance in providing care; interventions in this group involve the use of institutions such as adult daycares, at-home services, or hospices (World Health Organization, 2017).

Of the listed interventions, psychoeducational approaches and cognitive behavioral therapy (CBT) have been found to be most effective in reducing overall feelings of caregiver burden (World Health Organization, 2017). Psychosocial interventions other than CBT and organizational interventions have not been shown to significantly impact the mediation of caregiver role strain (World Health Organization, 2017). While the success of interventions may vary among caregivers, the World Health Organization (2017) has stated that the benefit of lessening caregiver burden outweighs any possible risks associated with using interventions. Although it is one of the most effective interventions, CBT cannot be delivered by nurses. However, psychoeducational approaches, such as teaching caregivers how best to administer medication or aid care recipients in bathing and toileting, can and should be taught by nurses to improve caregivers' competency in delivering care (Alzheimer's Association, 2019; Laparidou et al., 2018; Hagedoorn et al., 2019).

Nurses can also offer information to informal caregivers regarding available resources. Nurse are capable of working with these organizations to gain knowledge of how best to aid informal caregivers. The Alzheimer's Association, Alzheimer's Foundation, American Association of Retired Persons (AARP), and the Family Caregiver Alliance should be recommended to caregivers or contacted by nurses, as these institutions supply education regarding diseases processes, management of behaviors in patients with dementia, and available financial aid programs (Family Caregiver Alliance, 2017). Additional resources, if needed, might include Meals on Wheels or local services, such as a caregiving support group that meets at a church or community center (Family Caregiver Alliance, 2017).

Assessment of nursing education

Specific symptoms of role strain and interventions capable of reducing the effects of these symptoms on caregivers have been identified in past research, but assessing for burden and implementing appropriate interventions can be exceedingly difficult for healthcare providers if they have not received training on such issues (Chiao et al., 2015; Hengelaar et al., 2017). A study conducted by Greenwood et al. (2010) demonstrated that, although healthcare providers, including nurses, recognize that they are in a favorable position to mediate role strain, many of these professionals were not confident in their ability to recognize and prevent burden in informal caregivers. Further research regarding this issue done by Aujoulat et al., Carpentier et al., and Ward-Griffin (Hengelaar et al., 2017) found that providers believe emotional and psychological support is critical for informal caregivers; however, many did not consider themselves competent enough in such areas to offer support, and feared that they would provide inappropriate or incorrect advice.

When healthcare workers are unprepared to assess and respond to the needs of caregivers of dementia patients, they may inadvertently contribute to the development or exacerbation of role strain (Laparidou et al., 2018). Previous research has shown that if healthcare providers learn how to educate and collaborate with informal caregivers of dementia patients, the stress associated with informal caregiving is significantly reduced (Laparidou et al., 2018). Hengelaar et al. (2017) found that nurses do not feel as though they have been adequately taught how to aid informal caregivers, and it is thus pertinent to include the topic of informal caregiving and methods of supporting caregivers within nursing education.

Universities and their respective nursing programs have varied courses, and therefore each school must be assessed separately to determine which topics are included in its curriculum. This thesis project will focus on the University of Southern Mississippi's BSN program, and will involve a survey of students within the program and an examination of the program's curriculum. A grid of essential curriculum concepts covered within the university's School of Professional Nursing Practice was provided by Assistant Professor and thesis adviser, Dr. Lisa Green. This content grid was found to have no mention of the following terms relating to the topic of informal caregiving: *informal caregiving, informal caregiver, caregiver burden, caregiver role strain, informal care.* In the planned topics for the second semester of the program, the disease *dementia* was included in the required topics, as was the concept of *management of patients with Alzheimer's disease.* No other reference to dementia or Alzheimer's disease could be found within the University of Southern Mississippi's BSN curriculum.

Summary

Informal caregiving represents a critical aspect of the healthcare system, but the family members and friends of care recipients who comprise this group also represent a population that is extremely susceptible to developing caregiver role strain (Alzheimer's Association, 2019; Collins & Swartz, 2011). If not prevented or addressed early, the presence of informal caregiver burden can lead to a decreased quality of life and health conditions that may be chronic, such as anxiety, depression, and cardiac disorders (Alzheimer's Association, 2019; Irfan et al., 2017). Symptoms of caregiver burden may not be readily detectible at first. Often, the caregiver will, over time, experience changing feelings towards the care receiver, including anger with the care recipient's increased needs and denial towards the presence of dementia (Thompson et al., 2018).

Nursing professionals hold a critical role in recognizing role strain in informal caregivers due to their extended contact with patients and their caregivers; nurses may be the first to recognize the presence of burden associated with informal caregiving and implement interventions (Hagedoorn et al., 2019; Zegwaard et al., 2015; Chiao et al., 2015). While multiple methods of intervention relating to caregiver burden exist, the two most effective intervention techniques include CBT and education (Morelli et al., 2019). CBT must be delivered by a trained psychologist, as it is a specialized form of psychotherapy involving the discussion and adjustment of specific behavioral patterns (Society of Clinical Psychology, 2017). While nurses cannot deliver CBT, they are in a suitable position to educate informal caregivers on the diagnosis and prognosis of dementia, associated life changes, and caregiving skills (Laparidou et al., 2018; Hagedoorn et al., 2019). Nurses can also discuss available resources with caregivers, including local and national services meant to reduce strain in caregivers and supply financial and nutritional aid. Although nurses have the potential to reduce role strain in informal caregivers of dementia patients, past research indicates that many nurses have not been properly trained to assess for role strain and respond to its presence within clinical practice, which leads to little mediation of caregiver burden and may cause the condition to worsen (Laparidou et al., 2018).

For nurses to recognize and respond to informal caregiver role burden while in clinical practice, the topic should be discussed while they are still enrolled in nursing school. If concepts like caregiver burden are introduced early, nursing students will graduate from their programs and begin practicing with awareness of the issue, leaving them more prepared to encounter informal caregivers and address caregiver burden if faced with it in clinical practice (Hengelaar et al., 2017). Research should therefore focus on determining if nursing students, still within their programs, feel adequately prepared to assess for, recognize, and intervene with informal caregiver role strain. As a college with a four-year Bachelor of Science in Nursing program, the University of Southern Mississippi is one of many schools in the United States at which nursing students' knowledge regarding the assessment, prevention, and intervention of informal caregiver role strain among dementia patients should be assessed.

CHAPTER III: METHODOLOGY

Design

To measure students' self-reported ability to define and recognize role strain in informal caregivers, the researcher of this thesis developed a multiple-choice, descriptive survey with a quantitative methodology. There were twenty-four questions in the distributed survey. A total of seventeen nursing students within the USM BSN program both consented to participate and completed the survey. Participating students were in their second, fourth, and fifth semesters of the five-semester BSN program.

Survey results were divided by specific groups of questions and focus. The first question of the survey requested that students state their current semester within the nursing program to allow the researcher to determine if students in later semesters reported significantly different responses from students in earlier semesters. Questions 2 through 6 asked students about their knowledge of informal caregivers, including the definition of the term, the difference between formal and informal caregivers, the definition of informal caregiver role strain, and the prevalence of caregivers in clinical practice. Questions 7 through 11 asked students about their beliefs regarding how often informal caregiving leads to changes in the lives of informal caregivers, as related to finances, employment, and caregiver health statutes. The focus of questions 12 through 19 was students' self-reported comfort level recognizing the signs of role strain and mediating strain in the clinical setting and their views of nurses' ability to intervene with caregiver role strain. Questions 20 to 24 asked participants about their beliefs concerning the importance of providing education about informal caregivers and role strain while students are in a BSN program, as well as if students believed their current BSN program had adequately prepared them to collaborate with and support informal caregivers of dementia patients.

Setting

This research survey was distributed online using Qualtrics, a secure portal accessed through an email generated within the university email system.

Participants

The survey was distributed to all nursing students actively enrolled in the BSN program at the University of Southern Mississippi in the Fall semester of 2020. Potential participants could have included students in their first, second, third, fourth, or fifth and final semester of the program. A total of seventeen nursing students completed the survey, including those in their second, fourth, and fifth semester of the USM nursing program.

Procedure

The survey and informed consent were developed by the researcher using Qualtrics. Once these items were created, the researcher sought approval to distribute the survey to students from the USM Institutional Review Board (IRB). After receiving IRB approval, a link to the consent form and survey were distributed through email by the Assistant to the Dean for Academic Records and Advisement of the School of Professional Nursing Practice. The email containing the survey link was sent to nursing students of any level currently enrolled in the USM BSN program during the 2020 Fall semester.

Due to the online nature of the research, the informed consent was placed at the beginning of the survey. In the consent, the purpose and possible risks and benefits of the survey were outlined. Participants were unable to progress past the first page without first agreeing or declining to agree to the terms outlined in the consent form. The consent informed participating students that they could close the browser window at any time without penalty if they at any point wished to withdraw from the study. Furthermore, the consent notified students that the survey was not expected to take longer than ten minutes to complete.

The first question in the survey asked students to list their semester within the BSN program at the time of completing the survey. The purpose of this question was to determine if students in later semesters reported being better prepared to work with informal caregivers of dementia patients than students in earlier semesters of the program. The only identifying data collected was students' year in the BSN program; all other data collected was anonymous. The researcher completed data collection and analysis through Qualtrics. The researcher and thesis adviser were the only individuals to review the collected data.

Limitations

The first and perhaps most significant limitation for this research study was the limited experience of the principal investigator. Another limitation was the small sample size of participants. A third limitation was the researcher's inability to ensure that students remained fully engaged throughout all questions of the online survey.

CHAPTER IV: DATA ANALYSIS

Overview

A total of seventeen (*n* = 17) nursing students responded to the emailed survey invitation. Students who followed the email link to the survey were unable to answer any survey questions without first completing the informed consent. The seventeen students who agreed to the informed consent completed all twenty-five questions of the survey. The survey questions and consent can be found in Appendix A and Appendix B, respectively. Students' responses to survey questions are divided into tables based upon the focus of the question sets. An additional table, Table 5, lists notable responses of senior-level students.

The *question* column within the tables lists the number of the question in the survey, as well as the written question. The *total* column references the total number of students who responded to the question. Within the *strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree,* and *strongly agree* columns, the percentage of students who chose that specific answer choice is listed. Beside the percentage, the number in parentheses illustrates the number of students who selected that response. Similarly, for questions 7, 8, 9, 10, and 11, in Table 3, the answer choices were *never, rarely, often,* and *very often*. The percentage and the actual number of students who selected each answer are listed in the same format as the other tables.

Table 1

Table 1 below indicates the first question, which asked students to identify their semester within the five-semester BSN program at the time of completing the survey. As seen in Table 1, two of the seventeen students were in their second semester at the time of taking the survey. Thirteen students were in their fourth semester. Another two students were in their fifth and final semester of the USM BSN program. Therefore, two junior-level students responded to the survey, while a total of fifteen student respondents were in their senior year of the BSN program.

Demographics

Semester	First	Second	Third	Fourth	Fifth	Total
	0.00% (0)	11.76% (2)	0.00% (0)	76.47% (13)	11.76% (2)	*n* = 17

Table 1: Demographics

Table 2

Table 2 refers to Questions 2 through 6. These questions were centered around the definition of informal caregivers, informal caregiver role strain, dementia and its effects on patients, and students' self-reported understanding of these terms.

Attitude

Question	Strongly disagree	Some-what disagree	Neither agree nor disagree	Some-what agree	Strongly agree	Total
I understand the difference between informal and formal caregivers.	0.00% (0)	0.00% (0)	5.88% (1)	47.06% (8)	47.06% (8)	*n* = 17
Informal caregivers are uncommon.	17.65% (3)	47.06% (8)	5.88% (1)	23.53% (4)	5.88% (1)	*n* = 17
I am aware of the physical and mental effects of dementia on patients afflicted with the condition.	0.00% (0)	5.88% (1)	0.00% (0)	17.65% (3)	76.47% (13)	*n* = 17

I understand the definition of informal caregiver role strain.	5.88% (1)	0.00% (0)	5.88% (1)	23.53% (4)	64.71% (11)	*n* = 17
After graduating from the university’s nursing program, I will interact and collaborate with informal caregivers often in clinical practice.	0.00% (0)	5.88% (1)	11.76% (2)	47.06% (8)	35.29% (6)	*n* = 17

Table 2: Attitude

Table 3

Survey questions 7 through 11 asked students to rank how often they believe informal caregivers of dementia patients are affected by their status as a caregiver, as related to caregivers’ finances, employment, and health status.

Current Knowledge

Question	Never	Rarely	Often	Very often	Total
Informal caregivers of dementia patients may experience unexpected changes in working hours, such as going into work late or leaving early due to patient care needs.	0.00% (0)	0.00% (0)	70.59% (12)	29.41% (5)	*n* = 17
Informal caregivers of dementia patients may lose all sources of employment in order to provide care for patients full-time.	0.00% (0)	17.65% (3)	58.82% (10)	23.53% (4)	*n* = 17

Informal caregivers of dementia patients may be unable to afford housing, food, and clothing due to the medical care costs (i.e. physician's appointments, medications) of their patients.	0.00% (0)	23.53% (4)	58.82% (10)	17.65% (3)	*n* = 17
Informal caregivers of dementia patients may not have additional money to place into savings accounts as a result of the medical care costs (i.e. physician's appointments, medications) of their patients.	0.00% (0)	11.76% (2)	52.94% (9)	35.29% (6)	*n* = 17
Informal caregivers of dementia patients will experience a worsening of overall health status after beginning to provide care to dementia patients.	5.88% (1)	23.53% (4)	58.82% (10)	11.76% (2)	*n* = 17

Table 3: Current Knowledge

Table 4

Questions 12 through 19 centered around students' beliefs regarding nurses' ability to mediate role strain, as well as students' confidence in their ability to provide aid to informal caregivers of dementia patients after graduating the BSN program. The final questions of this thesis survey, questions 20 through 24, focused on students' opinions concerning nursing education. Specifically, students were asked if they believed that general nursing programs should include education about informal caregivers of dementia patients. Students were also asked if they felt that their current BSN program had prepared them to both recognize the signs of informal caregiver role strain, as well as intervene if role strain was present in informal caregivers.

Beliefs

Question	Strongly disagree	Some-what disagree	Neither agree nor disagree	Some-what agree	Strongly agree	Total
I would be comfortable working with informal caregivers after graduating the BSN program and entering clinical practice.	0.00% (0)	0.00% (0)	5.88% (1)	52.94% (9)	41.18% (7)	*n* = 17
Informal caregiver role strain is an issue that can be easily treated.	11.76% (2)	35.29% (6)	35.29% (6)	17.65% (3)	0.00% (0)	*n* = 17
Role strain in informal caregivers of dementia patients is preventable.	0.00% (0)	11.76% (2)	35.29% (6)	41.18% (7)	11.76% (2)	*n* = 17
After graduating the BSN program and entering clinical practice, I would be able to recognize the clinical manifestations (signs and symptoms) of role strain in informal caregivers.	0.00% (0)	0.00% (0)	0.00% (0)	58.82% (10)	41.18% (7)	*n* = 17
After graduating the BSN program and entering clinical practice, I would be able to offer informal caregivers advice regarding the management of role strain.	0.00% (0)	11.76% (2)	11.76% (2)	41.18% (7)	35.29% (6)	*n* = 17

There is little nurses can do to mediate role strain in informal caregivers.	29.41% (5)	41.18% (7)	17.65% (3)	5.88% (1)	5.88% (1)	*n* = 17
Training informal caregivers to provide caregiving skills (i.e. assisting care recipients with bathing, feeding, and toileting) can reduce role strain.	0.00% (0)	0.00% (0)	5.88% (1)	52.94% (9)	41.18% (7)	*n* = 17
Educating informal caregivers about the care recipients' disease (i.e. dementia) can reduce role strain.	0.00% (0)	0.00% (0)	5.88% (1)	35.29% (6)	58.82% (10)	*n* = 17
Nursing students should be educated about informal caregivers while in an undergraduate BSN program.	0.00% (0)	0.00% (0)	23.53% (4)	29.41% (5)	47.06% (8)	*n* = 17
Nursing students should be taught how to intervene with informal caregiver role strain while in an undergraduate BSN program.	0.00% (0)	0.00% (0)	0.00% (0)	47.06% (8)	52.94% (9)	*n* = 17
The BSN program has prepared me to recognize the clinical manifestations (signs and symptoms) of informal caregiver role strain.	0.00% (0)	5.88% (1)	0.00% (0)	70.59% (12)	23.53% (4)	*n* = 17

The BSN program has prepared me to mediate the presence of informal caregiver role strain.	0.00% (0)	11.76% (2)	23.53% (4)	41.18% (7)	23.53% (4)	*n* = 17
The BSN program curriculum has provided me with adequate education regarding how I can best meet the needs of informal caregivers and dementia patients.	0.00% (0)	5.88% (1)	29.41% (5)	58.82% (10)	5.88% (1)	*n* = 17

Table 4: Beliefs

Table 5

The goal of this thesis was to assess senior-level nursing students’ understanding of informal caregivers. Junior-level nursing students were also invited to take the survey, in order to determine if there was any correlation between further progression in a BSN program and greater knowledge regarding informal caregivers of dementia patients. A total of fifteen participants were in their senior year at the time of taking this thesis survey, while two of the respondents were in their junior year. Tables 1, 2, 3, and 4 include responses from all respondents, regardless of reported level in the nursing program. Notable responses from senior-level students have been pulled from the above tables and listed in Table 5 below.

Notable Results

Question	Never	Rarely	Often	Very often	Total
Informal caregivers of dementia patients may lose all sources of employment in order to provide care for patients full-time.	0.00% (0)	20.00% (3)	53.33% (8)	26.67% (4)	*n* = 15

Informal caregivers of dementia patients may be unable to afford housing, food, and clothing due to the medical care costs (i.e. physician’s appointments, medications) of their patients.	0.00% (0)	26.67% (4)	60.00% (9)	13.33% (2)	*n* = 15
Informal caregivers of dementia patients may not have additional money to place into savings accounts as a result of the medical care costs (i.e. physician’s appointments, medications) of their patients.	0.00% (0)	13.33% (2)	53.33% (8)	33.33% (5)	*n* = 15
Informal caregivers of dementia patients will experience a worsening of overall health status after beginning to provide care to dementia patients.	6.67% (1)	20.00% (3)	60.00% (9)	13.33% (2)	*n* = 15

Table 5: Notable Results

Summary

For this thesis, a twenty-four-question, Likert-type survey was emailed to all students actively enrolled in the USM BSN program during the Fall 2020 semester. A total of seventeen students responded to the email and completed the survey. Fifteen of the respondents were in their senior year at the time of taking the survey, and the remaining two survey participants were in their junior year. The intent of including students in their junior year of the nursing program was to determine if any significant differences in responses were present. Significant variances were not noted in the responses from junior- and senior-level nursing students, but it must be mentioned that only two of the survey respondents were in their junior year. Due to the small sample size of junior-level students, the survey responses from participants in this year of the BSN program may not be an accurate representation of all junior-level students.

Although no major differences were found between students in their junior or senior year, some notable responses were seen from senior-level students, as listed in Table 5. The purpose of this thesis was to assess senior-level students' understanding of and ability to work with informal caregivers of dementia patients in clinical practice. Questions 2, 3, 4, 5, and 6 were provided to assess students' self-reported knowledge about and comfort level when working with informal caregivers. Table 2 presents these questions and the responses from all seventeen students. The responses indicate that many of the survey participants (*n* = 15) believe they understand the definition of *informal caregivers*, and feel prepared to mediate role strain in informal caregivers upon entering clinical practice (*n* = 13). However, the responses to questions 8, 9, 10, and 11 do not support students' self-reported beliefs regarding their knowledge of the difficulties that informal caregivers face related to finances, employment, and health status (see Table 5).

Multiple senior students' replies were not supported by 2019 research from the Alzheimer's Association. Data from the Alzheimer's Association (2019) indicates that 6% of informal caregivers cease working, and 9% retire earlier than they originally anticipated to provide care to patients with dementia. Similarly, 48% of informal caregivers of dementia patients decrease personal spending, and 43% of informal caregivers reduce the amount of money they place into savings accounts to afford the medical costs of their care recipients (Alzheimer's Association, 2019). Additionally, 35% of informal caregivers report an overall worsening of health after they begin caring for an individual with dementia (Alzheimer's Association, 2019). Questions 8, 9, 10, and 11 assessed students' beliefs regarding how often they felt caregivers lost employment, decreased personal spending, reduced savings, and suffered from a worsening health state.

When asked how often they believed informal caregivers stopped working to care for a patient with dementia, three (*n* = 3) of the fifteen senior BSN students replied to question 8, stating they believed it rarely occurred. Similarly, to question 9, four (*n* = 4) senior-level students reported that they felt informal caregivers rarely had to decrease their personal spending in order to pay for their care recipients' medical costs. Two (*n* = 2) senior students, when asked in question 10 how often they thought informal caregivers had to reduce the amount of money they placed into savings to pay for the medical costs of their care receivers, responded that it was rarely true. Finally, in response to question 11, which requested that students state how often they believed informal caregivers suffered from an overall worsening of health due to providing care to a person with dementia, one (*n* = 1) senior student replied that this never occurred, and another three (*n* = 3) felt it was rare. These questions and senior students' responses, which are listed in Table 5, indicate that a discrepancy may exist regarding students' understanding of how caring for a person with dementia affects the lives of informal caregivers.

CHAPTER V: CONCLUSION AND RECOMMENDATIONS

Discussion

To complete this thesis, an online, Likert scale and multiple-choice survey was administered to nursing students within the BSN program at the University of Southern Mississippi in the Fall 2020 semester. Students were asked questions designed to assess their current knowledge of informal caregivers and caregiver role strain. Several questions also collected responses from students to determine their opinions of how well their BSN program had prepared them to collaborate with informal caregivers of dementia patients after graduating from the nursing program.

This thesis survey was dispersed through an emailed Qualtrics link to all students enrolled in the USM BSN program at the time of the survey's distribution. Although the focus of this research is on nursing students in their senior year, including the fourth and fifth semester of the nursing program, students of all levels were invited to participate. The researcher's intent when administering the survey to students of both junior- and senior-level was to determine if senior-level students reported a greater or lesser understanding of informal caregivers of dementia patients and role strain when compared to students in their junior year.

Of the seventeen students who completed the survey, ten ($n = 10$) somewhat agreed, and seven ($n = 7$) students strongly agreed that they would feel comfortable recognizing the signs of role strain in informal caregivers (Question 15, Table 4). Similarly, ten ($n = 10$) students somewhat agreed, and one ($n = 1$) student strongly agreed that the USM BSN program had adequately prepared them for assisting informal caregivers once in clinical practice (Question 24, Table 4). However, this self-reported comfort level was not supported by the responses to questions 8, 9, 10, and 11. To the statement in question 8, *informal caregivers of dementia patients may lose all sources of employment in order to provide care for patients full-time*, three (*n* = 3) of the fifteen senior level students answered that they felt this happened rarely. However, research completed by the Alzheimer's Association (2019) discovered that 9% of informal caregivers of dementia patients have stopped working entirely in order to care for dementia patients, and an additional 6% of caregivers retired earlier than they had originally planned to provide care to dementia patients. Question 9 stated, *informal caregivers of dementia patients may be unable to afford housing, food, and clothing due to the medical care costs (i.e. physician's appointments, medications) of their patients.* Four (*n* = 4) students in their senior year reported that they believed this rarely occurred. This answer selection is in direct contrast to research findings from 2019, which indicated that 48% of informal caregivers of dementia patients had to reduce personal spending in order to afford medical care for care recipients (Alzheimer's Association, 2019).

Similarly, in response to question 10, *informal caregivers of dementia patients may not have additional money to place into savings accounts as a result of the medical care costs (i.e. physician's appointments, medications) of their patients,* two (*n* = 2) senior-level students selected that they believed this was rarely true. Again, this choice of response is not supported by the annual report from the Alzheimer's Association (2019), which stated that 43% of dementia caregivers were forced to reduce the amount of money they place into savings accounts in order to afford the medical costs of their care recipients. Question 11 of the survey read, *informal caregivers of dementia patients will experience a worsening of overall health status after beginning to provide care to* *dementia patients.* As represented in Table 5, one senior student (*n* = 1) stated that they believed this never occurred, and another three (*n* = 3) students responded that they believed this rarely happened to informal caregivers. According to the Alzheimer's Association (2019), 35% of informal caregivers of dementia patients experience a worsening of overall health status after they begin providing care to a dementia patient. These results may indicate a need for further education in the BSN program regarding informal caregivers and the difficult life changes they may face as care providers to dementia patients.

Conclusion

Informal caregivers represent a significant population in the healthcare system, with over 16 million individuals in the United States serving as unpaid caregivers to patients with dementia (Alzheimer's Association, 2021). Because informal caregivers do not require payment, they are able to care for dementia patients who may otherwise be unable to afford medical care, or patients who are ineligible for care in a more formal setting, such as a nursing home (Collins & Swartz, 2011). In 2019, informal caregivers provided approximately 18.6 billion hours of unpaid care, the monetary value of which is equivalent to 244 billion dollars (Alzheimer's Association, 2021). Informal caregivers often aid patients in many or all their daily tasks, including bathing, feeding, toileting, shopping, and dressing (Alzheimer's Association, 2021). However, providing care to an individual with dementia is not easy, and various research studies have shown that informal caregivers of dementia patients may experience depression, anxiety, and worsening physical health due to caregiving demands (Alzheimer's Association, 2021). If unaddressed, these emotional and physical changes can lead to the development of caregiver role strain (Alzheimer's Association, 2021).

The COVID-19 pandemic has created additional distress for informal caregivers of dementia patients. Many social services, such as daycare centers, activity groups, and support groups, have been unable to meet in-person since the pandemic began due to public health regulations. As a result, dementia patients and their caregivers were forced to change their routines and stay at home for extended periods of time. Furthermore, routine appointments with dementia patients' healthcare providers were often canceled or pushed to a later date, leaving worsening symptoms unaddressed (Canevelli et al., 2020). In a study completed by Giebel et al. (2020), it was found that the isolation caused by the pandemic led to a lack of cognitive stimulation in dementia patients, which resulted in an increased rate of cognitive deterioration and a more intensive need for assistance with everyday tasks. This swifter decline in dementia patients and lack of outside support resources has, in turn, created increased levels of anxiety and role strain in patients' informal caregivers (Giebel et al., 2020; Canevelli et al., 2020; Savla et al., 2020). Because informal caregivers are unable to access many of the resources they utilized before the pandemic began, it is critical that healthcare professionals, like nurses, contact caregivers on a scheduled basis. Ideally, this contact would be maintained by a nurse, social worker, or another healthcare worker familiar with the patient and informal caregiver, as this would allow for the creation of a supportive, therapeutic relationship between a healthcare provider and an informal caregiver (Lucero et al., 2019). By communicating with informal caregivers regularly, such as on a weekly basis, nurses or other healthcare professionals can ensure that informal caregivers of dementia patients have access to the resources they need and are providing adequate care for both themselves and their care recipients (Canevelli et al., 2020; Lucero et al., 2019).

Amongst healthcare staff, nurses have the most contact with patients and their caregivers, thus placing them in an ideal position to recognize the signs of informal caregiver role strain and intervene before strain worsens (American Association of Colleges of Nursing, 2019; Hagedoorn et al., 2019; Chiao et al., 2015). The current healthcare climate heightens the concern for informal caregivers, as many caregivers have lost access to their previously used support resources (Canevelli et al., 2020). It is therefore especially critical for nurses to regularly assess informal caregivers for signs of role strain. To best aid caregivers, nurses should be educated about both informal caregivers and caregiver role strain while in a nursing program. If such techniques are provided, nursing students can enter into clinical practice with a general understanding of how to collaborate with and best support informal caregivers of dementia patients (Hengelaar, et al, 2017).

Recommendations

This thesis provides preliminary research concerning senior BSN students' understanding of informal caregivers of dementia patients. Survey responses were not statistically significant due to the small sample size and lack of experience of the principal investigator. However, the senior students' responses to questions 8, 9, 10, and 11 indicate that students may need additional education regarding the impact that caregiving has on informal caregivers. Students who are unaware of the stressors that informal caregivers face may be unable to intervene before these issues lead to the development or worsening of caregiver role strain. Further studies should be conducted regarding senior nursing students’ knowledge of informal caregivers to better determine if the education given in BSN programs is adequately preparing students to recognize and mediate informal caregiver role strain in clinical practice. Future research should also study BSN programs of more than one university to assess if there is any correlation between different curriculums and students’ knowledge of informal caregivers and caregiver role strain.

APPENDIX A: SURVEY

Survey Questionnaire to assess students' level in a BSN program, their knowledge of and attitude towards informal caregivers of dementia patients, and their beliefs of how well their BSN program has prepared them to collaborate with informal caregivers in a clinical setting.

Q1: Select which of the following best applies to you:

○ I am in the first semester of an undergraduate BSN program.
○ I am in the second semester of an undergraduate BSN program.
○ I am in the third semester of an undergraduate BSN program.
○ I am in the fourth semester of an undergraduate BSN program.
○ I am in the fifth semester of an undergraduate BSN program.

(Continued on next page.)

Q2-Q6: Provide a response to the following statements based upon your current knowledge of informal caregivers and role strain.	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
I understand the difference between informal caregivers and formal caregivers. (1)	○	○	○	○	○
Informal caregivers are uncommon. (2)	○	○	○	○	○
I am aware of the physical and mental effects of dementia on patients afflicted with the condition. (3)	○	○	○	○	○

I understand the definition of informal caregiver role strain. (4)	○	○	○	○	○
After graduating from the university's nursing program, I will interact and collaborate with informal caregivers often in clinical practice. (5)	○	○	○	○	○

(Continued on next page.)

Q7-Q11: With your current knowledge, how often do you believe the following occur as a result of role strain in informal caregivers of dementia patients?

Q7: Informal caregivers of dementia patients may experience unexpected changes in working hours, such as going into work late or leaving early due to patient care needs.

○ Never (1)
○ Rarely (2)
○ Often (3)
○ Very often (4)

Q8: Informal caregivers of dementia patients may lose all sources of employment in order to provide care for patients full-time.

○ Never (1)
○ Rarely (2)
○ Often (3)
○ Very often (4)

Q9: Informal caregivers of dementia patients may be unable to afford housing, food, and clothing due to the medical care costs (i.e. physician's appointments, medications) of their patients.

- ○ Never (1)
- ○ Rarely (2)
- ○ Often (3)
- ○ Very often (4)

Q10: Informal caregivers of dementia patients may not have additional money to place into savings accounts as a result of the medical care costs (i.e. physician's appointments, medications) of their patients.

- ○ Never (1)
- ○ Rarely (2)
- ○ Often (3)
- ○ Very often (4)

Q11: Informal caregivers of dementia patients will experience a worsening of overall health status after beginning to provide care to dementia patients.

○ Never (1)
○ Rarely (2)
○ Often (3)
○ Very often (4)

(Continued on next page.)

Q12-Q19: Provide a response to the following questions based upon your current understanding of informal caregivers and caregiver role strain.	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
I would be comfortable working with informal caregivers after graduating the BSN program and entering clinical practice. (1)	○	○	○	○	○
Informal caregiver role strain is an issue that can be easily treated. (2)	○	○	○	○	○
Role strain in informal caregivers of dementia patients is preventable. (3)	○	○	○	○	○

After graduating the BSN program and entering clinical practice, I would be able to recognize the clinical manifestations (signs and symptoms) of role strain in informal caregivers. (4)	○	○	○	○	○
After graduating the BSN program and entering clinical practice, I would be able to offer informal caregivers advice regarding the management of role strain. (5)	○	○	○	○	○
There is little nurses can do to mediate role strain in informal caregivers. (6)	○	○	○	○	○

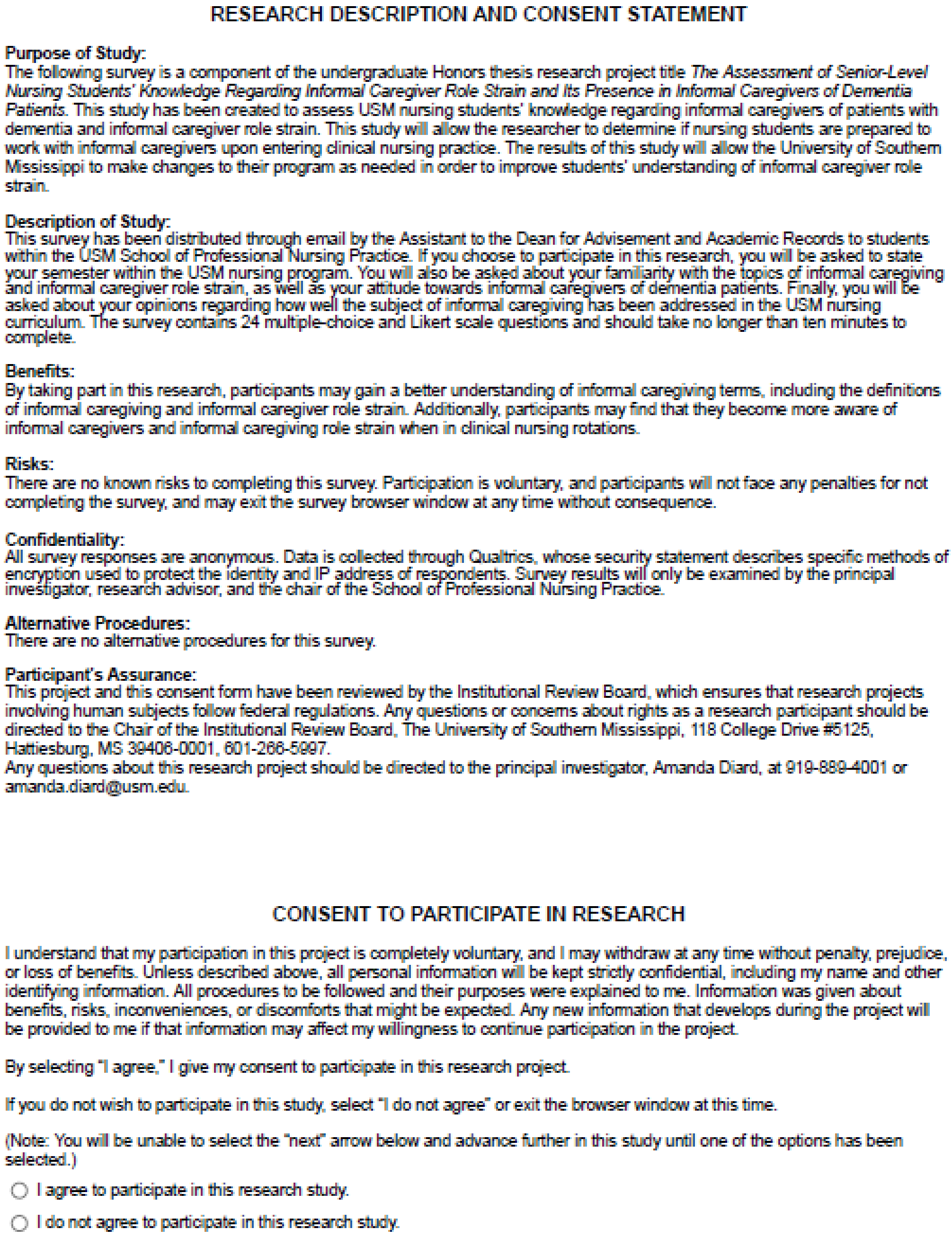
Training informal caregivers to provide caregiving skills (i.e. assisting care recipients with bathing, feeding, and toileting) can reduce role strain. (7)	○	○	○	○	○
Educating informal caregivers about the care recipients' disease (i.e. dementia) can reduce role strain. (8)	○	○	○	○	○

(Continued on next page.)

Q20-Q24: Provide a response to the following based upon your current opinions regarding the topic of informal caregivers of dementia patients in the BSN curriculum.	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
Nursing students should be educated about informal caregivers while in an undergraduate BSN program. (1)	○	○	○	○	○
Nursing students should be taught how to intervene with informal caregiver role strain while in an undergraduate BSN program. (2)	○	○	○	○	○

The BSN program has prepared me to recognize the clinical manifestations (signs and symptoms) of informal caregiver role strain. (3)	○	○	○	○	○
The BSN program has prepared me to mediate the presence of informal caregiver role strain. (4)	○	○	○	○	○
The BSN program curriculum has provided me with adequate education regarding how I can best meet the needs of informal caregivers of dementia patients. (5)	○	○	○	○	○

APPENDIX B: SURVEY CONSENT



RESEARCH DESCRIPTION AND CONSENT STATEMENT

Purpose of Study:
The following survey is a component of the undergraduate Honors thesis research project title *The Assessment of Senior-Level Nursing Students' Knowledge Regarding Informal Caregiver Role Strain and Its Presence in Informal Caregivers of Dementia Patients*. This study has been created to assess USM nursing students' knowledge regarding informal caregivers of patients with dementia and informal caregiver role strain. This study will allow the researcher to determine if nursing students are prepared to work with informal caregivers upon entering clinical nursing practice. The results of this study will allow the University of Southern Mississippi to make changes to their program as needed in order to improve students' understanding of informal caregiver role strain.

Description of Study:
This survey has been distributed through email by the Assistant to the Dean for Advisement and Academic Records to students within the USM School of Professional Nursing Practice. If you choose to participate in this research, you will be asked to state your semester within the USM nursing program. You will also be asked about your familiarity with the topics of informal caregiving and informal caregiver role strain, as well as your attitude towards informal caregivers of dementia patients. Finally, you will be asked about your opinions regarding how well the subject of informal caregiving has been addressed in the USM nursing curriculum. The survey contains 24 multiple-choice and Likert scale questions and should take no longer than ten minutes to complete.

Benefits:
By taking part in this research, participants may gain a better understanding of informal caregiving terms, including the definitions of informal caregiving and informal caregiver role strain. Additionally, participants may find that they become more aware of informal caregivers and informal caregiving role strain when in clinical nursing rotations.

Risks:
There are no known risks to completing this survey. Participation is voluntary, and participants will not face any penalties for not completing the survey, and may exit the survey browser window at any time without consequence.

Confidentiality:
All survey responses are anonymous. Data is collected through Qualtrics, whose security statement describes specific methods of encryption used to protect the identity and IP address of respondents. Survey results will only be examined by the principal investigator, research advisor, and the chair of the School of Professional Nursing Practice.

Alternative Procedures:
There are no alternative procedures for this survey.

Participant's Assurance:
This project and this consent form have been reviewed by the Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research participant should be directed to the Chair of the Institutional Review Board, The University of Southern Mississippi, 118 College Drive #5125, Hattiesburg, MS 39406-0001, 601-266-5997.
Any questions about this research project should be directed to the principal investigator, Amanda Diard, at 919-889-4001 or amanda.diard@usm.edu.

CONSENT TO PARTICIPATE IN RESEARCH

I understand that my participation in this project is completely voluntary, and I may withdraw at any time without penalty, prejudice, or loss of benefits. Unless described above, all personal information will be kept strictly confidential, including my name and other identifying information. All procedures to be followed and their purposes were explained to me. Information was given about benefits, risks, inconveniences, or discomforts that might be expected. Any new information that develops during the project will be provided to me if that information may affect my willingness to continue participation in the project.

By selecting "I agree," I give my consent to participate in this research project.

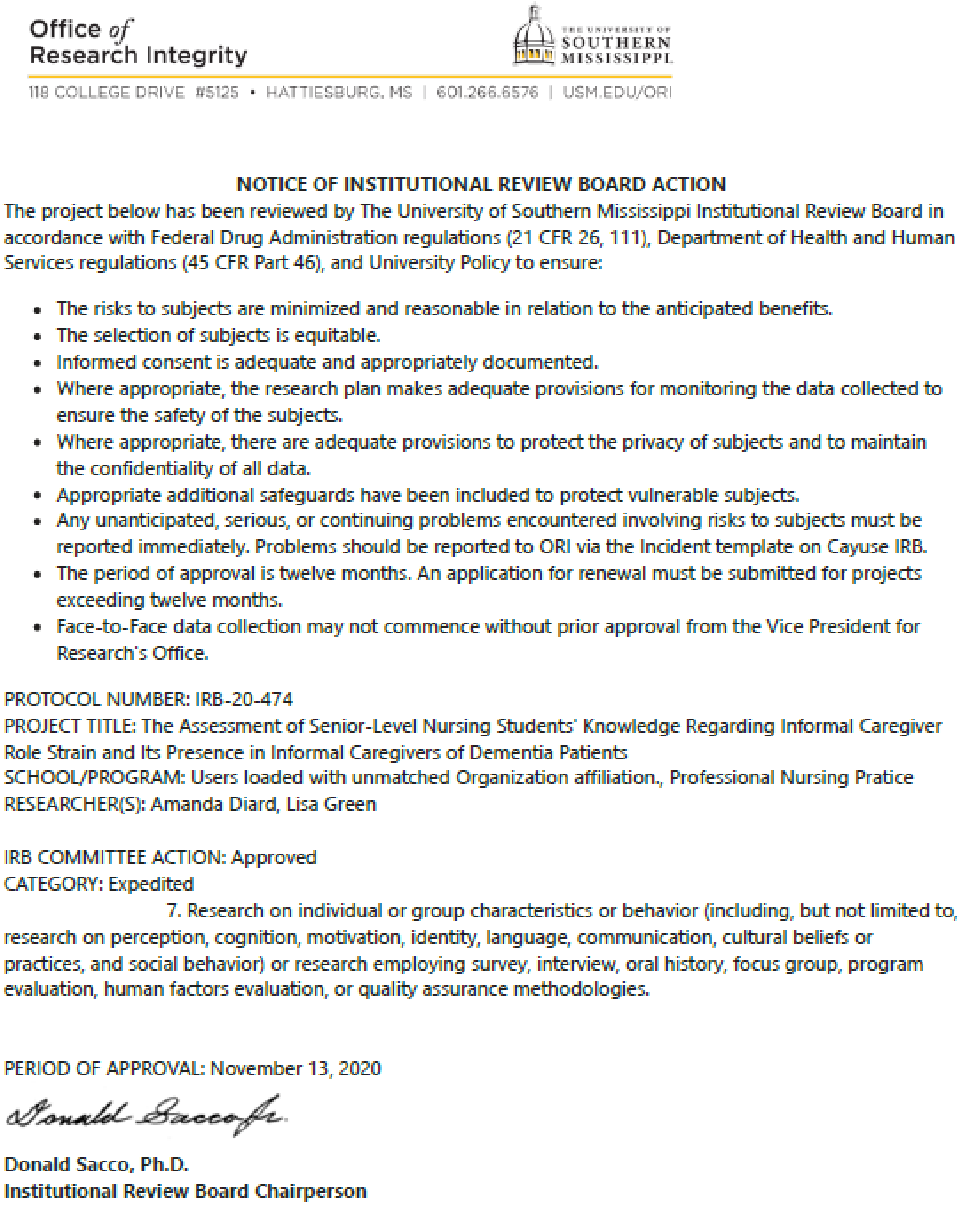
If you do not wish to participate in this study, select "I do not agree" or exit the browser window at this time.

(Note: You will be unable to select the "next" arrow below and advance further in this study until one of the options has been selected.)

○ I agree to participate in this research study.

○ I do not agree to participate in this research study.

APPENDIX C: IRB APPROVAL LETTER



Office of Research Integrity
THE UNIVERSITY OF SOUTHERN MISSISSIPPI
118 COLLEGE DRIVE #5125 • HATTIESBURG, MS | 601.266.6576 | USM.EDU/ORI

NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION

The project below has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered involving risks to subjects must be reported immediately. Problems should be reported to ORI via the Incident template on Cayuse IRB.
- The period of approval is twelve months. An application for renewal must be submitted for projects exceeding twelve months.
- Face-to-Face data collection may not commence without prior approval from the Vice President for Research's Office.

PROTOCOL NUMBER: IRB-20-474
PROJECT TITLE: The Assessment of Senior-Level Nursing Students' Knowledge Regarding Informal Caregiver Role Strain and Its Presence in Informal Caregivers of Dementia Patients
SCHOOL/PROGRAM: Users loaded with unmatched Organization affiliation., Professional Nursing Pratice
RESEARCHER(S): Amanda Diard, Lisa Green

IRB COMMITTEE ACTION: Approved
CATEGORY: Expedited

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

PERIOD OF APPROVAL: November 13, 2020

Donald Sacco Jr

Donald Sacco, Ph.D.
Institutional Review Board Chairperson

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